

Connie Lindberg

I am Connie Lindberg and I live in Minnetonka, Minnesota with my partner Steven Langsdale. As of the first of the year, we are officially empty nesters! I have two daughters Nikki who is married and has blessed me with 2 granddaughters and another grandchild on the way. My youngest Kelsey is a recent graduate and this past year was involved in the Pepsi Refresh program with IRSF.

Sara Brinkhaus is my grand niece and in 2000 she was diagnosed with Rett Syndrome. Her parents Dan and Lisa Brinkhaus founded the Minnesota Rett Syndrome Research Association (MRSRA) in 2001.

One the major fundraisers for MRSRA is an annual golf tournament. I can remember the first year so clearly!! We were at a smaller golf course and the banquet room had to be cleared of dishes, glasses, etc. before we could even attempt to set up for our event! The weather was not cooperating and some the golfers claim that they had snow on the course. A group of very dedicated volunteers did everything, setup, cooking, silent auction, you name, we did it. The golf tournament has since grown with moves to bigger and better courses.

I will be the first to admit that my personal involvement with fundraising and spreading Rett awareness was minimal. As the tournament grew, I continued to help with the banquet room setup and other than that I was a guest at the event. I wanted to do more, but was stuck on the idea that I needed to help in a monetary way and I just plain could not.

July of 2010 changed that! IRSF was competing in the Pepsi Refresh program and my niece Lisa had posted on Facebook to vote for Rett syndrome. Being the competitive person I am, I jumped in! I started watching the comments posted on the Pepsi page for Rett and made a random phone call to a group that was voting for Rett. Let's say my life took a wild turn! That phone call connected me with Mickie McCool and Donna Wright.

I was asked to be part of the committee to help IRSF win the 250K. My family would say that I was obsessed with the contest; I would argue that I was driven! I joined the Rettnet and started my Rett education. While I am not a parent of a Rett child and do not know the struggles personally, I am learning via the posts. There are some that make me smile, some that make me laugh, some that make me mad and way too many that make me cry.

I originally became involved in this contest to help Sara, but the deeper my involvement, I found I was in it to help Katie, Ellie, Ashley, Lena, Darleen, Naomi, Adrianna, Jordan, Cindy, Erin, and so many more.

The win for IRSF was bittersweet to me. I was joyous for the win, but sad that my involvement was coming to a close. Several people suggested I apply for the Family Advisory Board. I am grateful and excited to still be part of the "team" and look forward to continuing the drive to a cure.